

JOANNA M. GAUTHIER  
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September 19, 2018

Hon. Representative Hank Vaupel, Chair  
Hon. Representative Jim Tedder, Vice-Chair  
Hon. Representative Joseph Graves  
Hon. Representative Daniela Garcia  
Hon. Representative Jason Sheppard  
Hon. Representative Julie Calley  
Hon. Representative Diana Farrington  
Hon. Representative Roger Hauck  
Hon. Representative Pamela Hornberger  
Hon. Representative Bronna Kahle  
Hon. Representative Jeff Noble  
Hon. Representative Winnie Brinks  
Hon. Representative LaTanya Garrett  
Hon. Representative Sheldon Neeley  
Hon. Representative Jim Ellison  
Hon. Representative Abdullah Hammoud  
Hon. Representative Kevin Hertel  
HOUSE OF REPRESENTATIVES  
HEALTH POLICY COMMITTEE

Re: House Bill 5036

Dear Chair Vaupel and honorable members of the Health Policy Committee:

I am writing you to request your support for HB 5036 of 2017, which proposes creating an advisory council on Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) and Pediatric Acute Neuropsychiatric syndrome (PANS). PANS/PANDAS occurs when the immune system has a misdirected response to an infection, virus, or environmental toxin, which ultimately results in brain inflammation. The inflammation causes a variety of neurological and/or psychiatric symptoms that are life-changing and often debilitating.

My daughter (7), began exhibiting verbal and motor tics at the age of 4. She became cripplingly anxious about being away from me or our home. She began having meltdowns over little things that never bothered her before, like her stuffed animals being arranged "just so," being first on the stairs, or her pants having to match her shirt. She began refusing to wear socks, shoes, and underwear, and certain fabrics or textures drove her mad. She was now getting up multiple times during the night, afraid and anxious. She was clinging to me all the time. Over a short period of time, my happy, bright, adventurous child became anxious, depressed, and angry. She would say "I hate myself and my tics." We quickly became a family in crisis. During this time, the pediatrician said that tics are common in children and suggested that we should "wait and see" if the tics went away on their own. We returned to the pediatrician three times because the tics and ensuing behaviors did not diminish, but rather, continued to escalate.

It became clear after several months of this that we were losing our child – she was already a shell of her former self. By this time, there were days she could barely sit at the dinner table and use a

fork to feed herself. We thought she was having seizures, because she would sit and stare blankly into the distance while holding her fork. Despite professional opinions otherwise, this did not appear to be a medical condition that we could just “wait and see” about. Multiple visits with other specialists ensued, including an allergist, an ENT, a psychologist, and a neurologist. It was still suggested that we were dealing with “garden variety” Tourette Syndrome (“TS”) and that medication would be the only option. So we medicated, for 9 days, during which time my daughter became even more lost to us due to side effects of the medication. The neurologist even recommended stronger medications, including an antipsychotic.



Unconvinced by the TS diagnosis, and dissatisfied with the limited treatment options for it, we set out on a different path. We turned to a certified nutritionist/licensed psychologist for help, who recognized signs of immune issues (specifically PANS/PANDAS). We searched for a knowledgeable MD, bringing an integrative practitioner onto our team. We also learned what other families were attempting, doing trial and error with supplements, and investing significant time and resources in changing her diet. And we've seen some improvement. Today, more than 3 years after the initial onset, my daughter is attending 2<sup>nd</sup> grade in a public school, learning karate, and attending playdates like many of her peers. But she continues to experience constant motor tics, accompanied by frequent associated physical pain, emotional outbursts, OCD, and bouts of anxiety.

I continue to be incredibly thankful a medical expert recognized that the “garden variety” TS behaviors were actually being caused by a misdirected immune response (PANS/PANDAS), and I also often wonder what would have happened if the other medical experts had been knowledgeable enough to recognize it at the beginning of this journey. Immediate treatment may have had a more profound effect. As it stands now, we don't know what the future holds for her.

The advisory council proposed by HB 5036 would be instrumental to understanding PANS/PANDAS and the practicalities of treatment. The advisory council could make recommendations on standard practice guidelines, develop mechanisms to increase public awareness, provide outreach to educators and parents, and increase the understanding of the burden on Michigan caused by this condition and its related conditions. All of these practices are crucial to ensuring proper diagnosis and treatment, as well as supporting the affected families and communities.

Please support HB 5036, and in doing so, support the healing of my child and other children in Michigan. Thank you for your consideration. If you have any questions, please feel free to contact me.

Sincerely,

A handwritten signature in cursive script that reads "Joanna M. Gauthier".

Joanna M. Gauthier